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ABSTRACT

Discussion of the dynamics of individualized funding for providing services to people with developmental disabilities focuses on how individual funding may drive the changes necessary to develop services that offer highly customized assistance. This discussion considers why the concept of paying customers is powerful but misleading in light of such realities as the mismatch between what is wanted and what is offered, the lack of competition in the market for developmental disability services, and the need for customized services to be provided not at a single point but over long periods of time as people's requirements change. It suggests that what is needed is a market that stimulates innovation. Policymakers are urged to harness three interlocking processes: variation (many agents pursue different strategies in a shared environment); interaction (agents create exchanges, make use of things, and inform themselves about other agents' strategies; and selection (of some strategies over others). The paper suggests that a system with the best chance of continuing adaptability and success must have: (1) lots of agents; (2) some connections among agents; and (3) willingness and ability to try and tell. Policies and structures are judged by the criterion of whether, over time, people with disabilities and their families are more able to act as agents in customizing the assistance they require. (DB)

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Paying Customers Are Not Enough: The Dynamics of Individualized Funding

by
John O'Brien

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John O'Brien

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Individual funding is right for the times

Efforts to reform services to people with developmental disabilities by shifting to individualized funding have taken hold. Much has been accomplished in the way of articulating principles, advancing arguments for individualized funding, developing structures for allocating reasonable shares of funds to individual budgets, brokering services, and assuring an accountable flow of money. Debate about individualized funding has played an important role in defining new terms for understanding disability policy and encouraged many people who work for positive change (Stainton, 2000). Less has been said about the dynamics of individualized funding. A discussion of the dynamics of individualized funding turns on the question, **"How will individualized funding drive the changes necessary to develop services that offer highly customized assistance?"**

Advocates emphasize the rightness of individual funding. They see individualized funding as a tool to leverage the shift in power relations between service providers and their clients which a growing consciousness of rights demands. Conviction that enforced dependency on service providers violates people's rights calls for individualized funding to provide the heat that paying customers can apply to unfreeze a system stuck in controlling people.

The move to individualized funding is right. But I am sober about how powerfully the forces of paternalism and bureaucratic-professional control dominate the field and how slippery rhetorical conversions to self-determination can be. Conviction about the rightness of individual funding leads me to look for different ways to understand the conditions for its success. The destination matters so much that the vehicle must be thoughtfully designed, and thoughtful design calls for a careful look at the metaphors that excite enthusiasm. In the move to individualized funding, the idea of becoming paying customers excites people, so it merits consideration from different angles.

Some think the dynamics of individual funding obvious. Paying customers plan and shop, usually with the help of an independent broker. They pick and pay for what they want. If they are dissatisfied, they take their business elsewhere. Innovation happens when paying customers demand a new or better service. Providers either supply what people want or lose income to those who will. Demand from paying customers creates supply through the accumulation of straightforward buy-sell transactions.

"Brokering" is shorthand for a variety of functions that assist people to deal with the transaction costs of necessary assistance. These functions include: gathering a circle for support, making plans, qualifying for an adequate individual budget, selecting and organizing suitable service providers, and negotiating needed changes. There are many different ways to perform these functions.

Those with experience as brokers can reasonably criticize this paper as understating their contribution and therefore unfairly simplifying the position of the "paying customer". This may be so, but the temptation to allocate difficult systems problems to brokers justifies moving brokers into the background to allow a different view of the system. Any practical effort to implement individualized funding will rescue brokerage functions from the background.

This obvious answer obscures important facts about our system's current reality. Ironically, these same facts drive advocacy efforts in the first place: service systems control people too much and have proven easier to expand than to transform. The collision between these difficult realities and the expectation of buying services in the same way that we hire craftspeople to remodel our kitchens and frustrates both customers and providers and cuts off the energy necessary for innovation at the source.

An interesting and demanding idea of the way individualized funding creates change can be drawn from the study of complex adaptive systems. This perspective defines people with disabilities and their families as agents whose relationships with service providers and connections with other actors shape innovation, not as consumers who choose from providers' menus. They underline the importance of individual funding as a powerful means of increasing the variety of strategies that will create new pathways to valued roles in community life.

Because my study of this provocative field has been superficial, my sketch of the dynamics of individualized funding will be a rough cartoon that will serve its purpose if it stimulates better drawings by more knowledgeable people. Because this is an exploratory venture, it is short on immediate advice about what people with disabilities and their families should do, though it strongly supports their continuing struggle to create better supports for themselves, regardless of the bureaucratic implementation of individualized funding. I hope that the next steps from here include applying this perspective to the description of some efforts to implement individual budgeting. This will enrich a framework of thoughts with the stories of people and the strategies they have invented.

Why the idea of paying customers is powerful but misleading

It's easy to understand being a paying customer, and becoming one appeals to many people with developmental disabilities and their families because it promises them more control over their lives than depending on block purchasing by a public authority does. Paying customers choose what they want to buy based on their own preferences rather than accepting what a public official decides meets their professionally defined need. Paying customers look for good deals and make their own decisions about what to do when available funds won't cover all that they want. Paying customers voice orders and complaints that workers had better heed if they want their salaries. Paying customers take their business elsewhere if they are unhappy or if another

vendor offers a better deal. Paying customers hold a valued role in our consumer society and beneficiaries of government welfare services do not. Paying customers determine who succeeds and fails in the marketplace and thus assure a satisfactory allocation of scarce resources. Paying customers drive innovation as providers compete to discover and supply their unfulfilled desires.

This compelling image of the paying customer mobilizes many people who are dissatisfied by the current service system's inability to deliver the assistance people with developmental disabilities require in a way that respects human rights and dignity. But as powerful as the image of the paying customer is, its appeal as the answer can obscure four important facts about current reality:

- Most existing services are not designed to support advocates for change as they would prefer
- The market for developmental disability services is so tight as to nearly stifle competition because it has been centrally planned and chronically under-funded
- There are relatively small numbers of buyers and sellers of many services
- Satisfactory services deliver a high level of customization and usually not just at a single point but over long periods of time as people's requirements change

Mismatch between what's wanted and what's offered

Advocates for individualized funding have a clear idea of the sort of thing they want to purchase for themselves or their family members and friends. Most activists who speak out in conferences and planning groups say that they want to be in charge of exactly the assistance they need to pursue the friendships and relationships that make their lives good, to live in their own home, to work at a job that suits them, and to make the most of the local leisure, learning, and civic opportunities that match their personal interests. But in many places these demands are hard to fill for at least three reasons.

- Most existing services were designed to house, occupy, treat, and supervise groups of people with disabilities. For years policy debates concerned the professional identity of those in control, the size of the groups, the sort of buildings people with disabilities would use, and the kinds of programming staff would deliver. The resonant call for self-determination interrupts these debates and promotes individual or family choice into first place. In the scramble to assimilate this priority it is no wonder that words run well ahead of everyday organizational realities. However, people who want

personalized support want to purchase more than new labels on usual practice in congregate services.

- Current policy often reserves supported living or supported employment for people who meet particular cost or readiness criteria. People who require substantial accommodations or a lot of assistance often get left out. Even people with low-support needs who live in group facilities can find the move to supported living difficult when rules dictate that supported living costs cannot exceed their current cost of placement.
- Not every service labeled supported living or supported employment does the work necessary to personalize supports and assist people to exercise control of their day to day lives. Offering good support requires a kind of disciplined, continual organizational learning that many agencies currently lack the skills to do (O'Brien, Lyle O'Brien and Jacob, 1998).

According to Braddock and his colleagues (2000), in the US in 1998, about one in five participants in day services were in supported or competitive employment services, which can offer people a chance at a job that suits them, and about one in five residential places were categorized as supported living, which can offer people a chance at a home of their own. Though supported living is growing rapidly in the US as a whole, group residences continue to dominate both current provision and new development in a number of states, including the four most populous : California, Texas, New York. and Florida. Systems like New York State's that announce a strong verbal commitment to self-determination must grasp a contradiction between personalized supports and the highly regulated congregate services they continue to produce .

A tight market

Drive around a typical interstate highway exit and notice more than one gas station, more than one fast food outlet, often more than one motel. No single authority stands to get in political trouble for idle gas pumps, empty restaurant seats, or unfilled motel beds; slack capacity is built into the price of the gas, the burgers, and the beds. But the developmental disability service economy has been centrally planned to squeeze out the redundancy that makes competition possible. Its clients are too often like tired travelers turning off a remote stretch of highway late at night and scanning anxiously for "Open" or "Vacancy" signs.

This market tightness effectively adapts the system to the desire of most legislatures to keep very large numbers of eligible people waiting for needed services. It's hard to justify unused residential places or expenditures on start-ups when thousands of people wait at home with elderly parents and hundreds of people languish in nursing homes. This lack of excess capacity confers a big advantage on existing providers.

Central planning by developmental disabilities system administrators in response to legislative appropriations controls the rate at which new service providers enter the market. Reallocation of funds to new providers often generates resistance from existing agencies' constituents, so most new provider agencies are founded on new money. New money becomes available as a result

Advocates for individualized funding may be impatiently saying to themselves, "The answer is obvious: people with disabilities should be entitled, by right, to sufficient individual funding to meet their needs for assistance. The burden should be on governments to prove that a person does not need a requested support, and not on a person to prove that they have a legitimate need."

This seems good to me. However, this sensible doctrine describes an as yet unrealized political victory. In the meantime, implementers of individualized funding schemes engage the contradictions of creating a market within an underfunded bureaucratic system whose official mission is to administer grants of privilege. In such a system it will be difficult for people and their brokers to win at the person-centered planning table what has not been won in the legislature. If this is true, it is puzzling that many US demonstrations of individualized funding spend far more effort designing bureaucratic structures to treat individuals as consumers than they invest organizing collective action by citizens serious about claiming an entitlement to income transfer. (For a contrasting example of collective action to increase people's control of the supports they need, learn about the "There's No Place Like Home" Coalition at http://soeweb.syr.edu/thechp/coalition.html)

of well organized political action or because of political pressures generated by law suits or enforced compliance with regulations rather than unmet customer demand. It is not as consumers but as political organizers, lobbyists, participants in civil disobedience, defendants, and officially observed victims of conditions that violate funder's rules that people with disabilities and their families influence the level of money available to the current system. So new money usually goes to fix a problem imposed on the system. Successful lobbying to fund young people leaving school makes them preferred customers and opens the possibility for new providers to emerge to meet their needs. Members of classes protected by court decision or inmates of institutions in violation of regulations generate a demand for new services that can be filled by new providers if central planners decide to invest in paying start-up costs.

Not only does the amount of money people have to spend in the service market vary depending on their position in the system's political priorities, the overall service market involves fewer participants and fewer transactions than many consumer markets do. In 1996, total expenditures by the US DD system amounted to about $22.8 billion (Braddock, 2000). In the same year US consumers spent about $56 billion on soft drinks (Standard & Poor's *Food & Beverage Report*, 1996). Lessons about the ways tens of millions of consumer choices affects cola offerings hold up poorly in a controlled market with many times fewer instances of consumer decisions.

A crude but serviceable formula for innovation calls for producing things or experiences that lots of people will want at prices that more and more people will be able to pay as experience and increasing volume of production bring down costs. Test the requirements that most people with developmental disabilities have for assistance against this formula and it becomes clear why venture capitalists have been more interested in electronic doodads than in support services and why the stock market has proven more interested in seeking profit in congregate care or mass produced home health care than by investing in personalized assistance. Many people with developmental disabilities require a level of assistance that costs more than they and most of their families can afford to pay, so they depend on grants of public funds, whether or not they are also granted the privilege of spending the grant

through individualized funding. Furthermore, the costs of producing satisfactory assistance more likely rise than decline as the desire for competence and continuity in staff meets the growing scarcity of people interested in providing personal assistance.

According to the mother of one person involved in an individualized funding demonstration, the state grants $35,000 a year to pay for the assistance her son is assessed to need. The person's need for assistance will endure throughout his life. Shouldering this expense would be about the equivalent of paying full tuition at a private college every year for the rest of the person's life. The amount of assistance required and its cost will fluctuate somewhat, but within limits that will keep the cost substantially beyond most people's means.

Because competition is limited by lack of surplus capacity and barriers to the entry of new providers, existing providers have considerable power in deciding how to meet demand for new types of services. They can develop customized assistance. Or, they can define a paying customer's order as "unrealistic" and offer a clearly labeled substitute. "No one who is that low-functioning can work, so supported employment is out. But we will admit her to our medical day care program." Or, they can create confusion by re-labeling small changes in current services as just what the customer asked for. "What last month was our group home is now a 'home of your own'. Meet the five housemates you have chosen to live with." Because demand is often urgent, reasonable people who can't take their business down the road may decide to settle for what they can get. They may conclude that desire for a home, a job, and friends is a silly daydream. They may even organize to protect the services they have against the efforts of dreamers who demand customized assistance to live in their own homes and work at jobs of their choosing.

Requirement for high customization

Though the scale of expenditure is far smaller, buying satisfying assistance is less like buying a house than it is like purchasing engines for a commercial jet plane. House buyers search for a suitable property, negotiate the best possible terms, and move in. The seller fulfills contractual responsibilities and moves on, leaving the buyers responsible for the upkeep and improvement of their purchase. In contrast, airlines collaborate with airframe builders like Airbus or Boeing and engine builders like General Electric or Rolls Royce to develop the engines they require (Sabbagh, 1996). They negotiate design criteria as well as plans, production methods, and prices. If skillful, these negotiations result in important innovations in the engines themselves. Airlines buy into a long-

term relationship that includes training for their personnel, provision of parts, continuing problem solving, and re-engineering for improved performance. If the airline is smart, it nurtures this collaboration as a source of mutual benefit over the life of the engine.

A helpful objection to the jet-engine analogy would point out that aircraft engines are engineered things while long term assistance arrangements coordinate the efforts of people who have diverse and important purposes of their own. Exactly so. A physicist retired from the Jet Propulsion Laboratory, who is the parent of two men with autism, said, "Supported living, being primarily about people, is a lot harder than rocket science, though nowhere near as well paid."

At any rate, effective assistance can't be kept in inventory, ordered off the shelf, shipped away for warranty repair, or returned for money back. It is created by people's interactions and, like electricity, it is consumed at the moment of production. Paying customers use most of their allocated money to make it possible for capable people to join their lives in respectful and helpful ways. Effective service providers are developers, suppliers, and supporters of capable people. Paying customers get best value for their money when they see themselves as investors in collaborative relationships that yield positive experiences for their assistants as well as for themselves.

Creating an innovating market

Overcoming the mismatch between what people want from the developmental disabilities service system and what the system currently delivers calls for a market that stimulates innovation. The study of complex adaptive systems (Axelrod and Cohen, 1999) draws attention to key questions for designers of individualized funding initiatives to answer as they develop structures for allocating funds, supplying brokers, and managing funds. It also highlights the role of people with disabilities and their allies as the kind of customers who negotiate and collaborate with providers when they are not themselves the designers and managers of the supports they require.

Students of complexity suggest looking at the creation of markets that stimulate innovation from the point of view of complex adaptive systems. Such systems emerge and change as many players adapt to each other in circumstances that make it very hard to predict and control outcomes. In complex adaptive systems order evolves through a history of interaction among separate agents rather than from the imposition of central plans. To put complexity to work in generating the innovations necessary to support

people's self-determination, policy makers do what they can to harness three interlocking processes: variation, interaction, and selection.

Variation means that many agents pursue different strategies to get what they want in a shared environment. Strategies are the ways agents respond to their environment and pursue their goals. Many different strategies might lead people to jobs or homes or opportunities to learn, and more difference among strategies expands possibilities for all. Variation raises two key system design questions: 1) What is the right balance between variety and uniformity? and 2) How can the number of agents be increased to create variety that could matter? Looked at from the perspective of variation, individual funding could be a way to multiply the number of agents influencing the emergence of new power relationships and new offerings in the service system.

Interaction makes a complex adaptive system come alive as agents create exchanges, make use of things, and inform themselves about other agents' strategies and thus shape social patterns. Interaction raises two key system design questions: 1) What kinds of interactions should be able to happen and when? and 2) What rules will allow useful patterns of interactions to emerge? Looked at from the perspective of interaction, individual funding could be a way to increase the kinds of exchanges that people with disabilities and their families can initiate to include such possibilities as deciding to organize their own system of assistance; selecting provider organizations and negotiating where and how and from whom they receive assistance; investing in home ownership or further education and training; and choosing the organizations and people they want to collaborate with outside the developmental disabilities system.

Selection promotes adaptation by determining which strategies should be copied and which strategies should be abandoned. Selection raises three key design questions: 1) What criteria will define success? 2) How, and how frequently, will success and failure be attributed? and 3) How will successful strategies be copied and recombined into new strategies? From the point of view of selection, individual funding offers the means for people and their families to exert selection pressure on different strategies for assistance and

Resources on Complexity

Robert Axelrod and Michael Cohen (1999). *Harnessing Complexity: Organizational Implications of a Scientific Frontier.* New York: The Free Press. Though the authors would flinch at what I have done to their elegant theoretical discussion, this is the primary source for my cartoon application of complexity ideas.

John Holland (1995). *Hidden Order: How Adaptation Builds Complexity.* Reading, MA: Addison-Wesley.

Stuart Kauffman (1995). *At Home in the Universe: The Search for Laws of Self-Organization and Complexity.* New York: Oxford University Press.

Mitchell Waldrop (1994). *Complexity: The Emerging Science at the Edge of Order and Chaos.* New York: Simon and Schuster. This is the best place to start, it introduces a range of ideas about complexity by telling the stories of the people who founded the Santa Fe Institute.

Much of the work on complexity and its applications originates from The Santa Fe Institute www.santafe.edu. Recently the consultants Ernst and Young have begun to explore the business applications of these ideas in their online journal at www. businessinnovation.ey.com/journal.

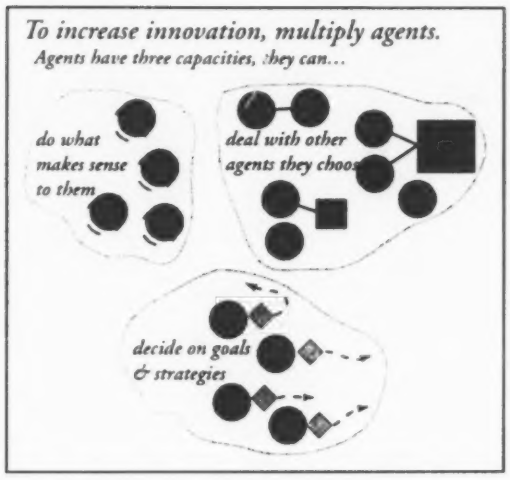
the occasion to shape exchanges of knowledge that will promote copying of successful strategies.

Conditions for success

Students of complex adaptive systems suggest selection criteria to test the many strategies proposed or tried in the name of self-determination, individual budgeting, and direct payments. A system with the best chance of continuing adaptability must meet three conditions: 1) Lots of agents; 2) Some connections among agents; 3) Willingness and ability to try and tell.

Lots of agents

As understood in the context of individual funding, agents have three necessary capacities. They can initiate action (do). They can negotiate (deal). They can make decisions in terms of their goals and in light of their memories of the results of other strategies (decide). The term agent is helpfully ambiguous. An individual person with a developmental disability acts as an agent. A person and family and friends and a broker act together as an agent. An individual personal assistant acts as an agent. A service organization acts as an agent. Each agent seeks to implement strategies that lead them closer to their goals.


To increase innovation, multiply agents.
Agents have three capacities, they can...
do what makes sense to them
deal with other agents they choos
decide on goals & strategies

A successful implementation of individual funding multiplies the number of people and organizations with the capacity to do, deal, and decide and the range of matters they can make deals on and decide for themselves. A minimum of enforceable rules sets limits on what agents can do within the system and protects the integrity of the deals that agents negotiate. People need to provide fair working conditions. The system might choose to limit prices. The governing body responsible for allocating funds might interpret anti-discrimination laws such as the Americans with Disabilities Act as forbidding the use of their funds to pay for segregated service settings.

People with disabilities and their families and friends will see and respect themselves, and be seen and respected by service workers and agencies, as negotiators of productive relationships rather than as either clients who must settle for whatever the system offers or sovereign consumers who expect unquestioning obedience.

For many people with disabilities and their families, acting as an agent presents new demands. The role of client in a highly professionalized service

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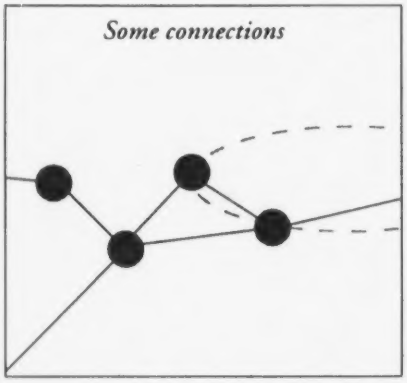
system can strip people of opportunities to develop their competence as definers of personal goals and negotiators of the arrangements they need. Connections and information can improve confidence and skill.

Some connections.

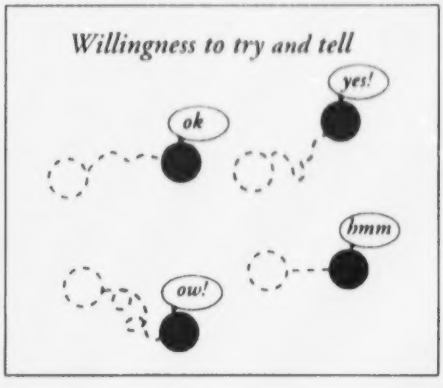
Connections allow and shape the flow of knowledge, the development of joint ventures, and the pooling and leveraging of resources. If connections between agents are too tight, there will likely be too little variety of strategies. If connections are too loose, there will be too little flow of knowledge and resources to allow the discovery, copying, and recombining of successful strategies.



A successful implementation of individualized funding will encourage connections, especially connections among people with disabilities and their families and connections to social worlds unfamiliar with people with developmental disabilities. Budgeting for internet access and training, transportation and personal assistance for attendance at advocacy group meetings and actions, creating and participating in learning events such as Partners in Policy Making, and support for people who play key connecting roles encourage connection. Extending bridges into different social worlds, such as has happened in the realm of home finance (O'Brien and Lyle O'Brien, 1999), enriches the network's possibilities by mobilizing new resources.

Willingness to try and tell.

Only strategies that are tried in action can influence the emergence of system adaptations. Visions on paper, no matter how grand, have far less impact on the world people live in than the steps, no matter how small, that people take to realize their visions. To be copy-able, enacted strategies need to become matter for sharing and reflection: What did we do? What worked? What didn't work? What did we learn about our goals? What will we try next?



A successful implementation of individualized funding will encourage people and agencies to describe and broadcast their strategies so that other agents can copy and combine what others have learned. Much of this reflection and strategy sharing will happen through personal or e-mail connections, but finding better ways to gather and broadcast the lessons of thoughtful action remains important.

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For the stories of individual and family agency...

Visit the website on Individual Funding maintained by Brian Salisbury and Steve Dowson http://members.home.net/tsalisbury/ This site provides access to many other resources on individualized funding and, along with their listserv on Individualized Funding is a fine example of facilitating trying and telling.

Beth Mount and Connie Lyle O'Brien, C. (2000). *Lives in transition.* New York: JobPath

John O'Brien and Connie Lyle O'Brien (2000) *Walking toward freedom: One family's journey into self-determination.* Seattle, WA: The Center for Community Support. Download from The Center on Human Policy, http://soeweb.syr.edu/thechp

Ann Turnbull and H. Rutherford Turnbull (1999). Comprehensive lifestyle support for adults with challenging behavior: From rhetoric to reality. *Education and Training in Mental Retardation and Developmental Disabilities 34(4)*, 373-394.

Trying and telling suggests a different sort of competition than the simple picture of providers exploiting trade secrets to win customers does. In a market driven by innovation, viability depends on the fit between provider offerings and customer values. In the search for customized assistance at public expense there are few if any patentable secrets of production. Ways to make public funds do new tricks are matters of public record. Ways to create desirable outcomes with people are usually more a matter of forming local and specific relationships than of applying a secret formula. Innovative methods for scanning for local resources, accounting, recruiting, scheduling, training, tracking activities, and record keeping can confer an advantage when they support effective relationships, and some of these may become a source of income when sold, taught, or licensed. But both people with disabilities and service providers will do better overall in a try and tell environment than they will in an environment of secrecy.

A system that increases adaptability encourages trying and risking. In such a system, people will take the time and trouble to build the kinds of relationships that provide resilience when failures happen rather than counting on central authorities to rule away risk. System managers will develop a variety of ways to offer insurance against accidents and avoid the temptation to second guess agents' considered plans.

A system that increases adaptability invests in making everyone smarter by investing in time and help for reflection, evaluation and description of strategies, and gatherings that build networks and encourage the exchange of strategies. Opportunities to get smarter include people with disabilities, family members, and direct service workers as well as managers and professionals.

From consumer to agent

Look in the dictionary. Consumers use things up; agents make things happen. Consumers buy what's already there; agents make deals that open new possibilities. Consumers wait for providers to offer answers; agents join in defining and creating what they value. Consumers can be grateful or grumpy about the service, appreciative or annoyed about what's offered; agents creatively raise and resolve conflicts. Consumers expect to be fed; agents cook.

The rate of transition from consumer to agent measures the degree of success of individualized funding. The most important test of any policy or structure is this one: ***Over time, will this make it easier for more people with disabilities and their families to act as agents in customizing the assistance they require?***

This is a tough transition and not everyone wants to make it. Many parents of people with disabilities yearn for a time when they can simply be their adult child's mom or dad without having to act as advocate, (back-up) personal assistant, and primary service coordinator. Joining their adult son or daughter in shaping the capacity for individually customized assistance moves them away from resting in this desired simplicity, at least in the intermediate term. Many people with developmental disabilities have learned how to be satisfied consumers of whatever service they currently get. They may have trouble imagining what life might be like with better fitting assistance or they may find the idea of sustained collaboration with a team a drag on their desire to get on with their life as is, with as few hassles as possible.

The Council on Quality and Leadership maintains a data base that summarizes the results of its accreditation visits to service agencies in the US. According to Council surveyors, who interviewed people with developmental disabilities and those who knew them best across living arrangements from institutions to people living in their own homes, 83% report satisfaction with their services and 81% report satisfaction with their personal life situations. Use the Council's database at www.ncor.org

Given the difficulty of moving from consumer to agent, it's good that students of complex adaptive systems say that significant change can happen without everyone making the transition at once. In fact, people who move later may be able to move farther and faster by avoiding what others have already discovered as blind alleys and following paths that others have found rewarding. A steady increase in the rate of people choosing the hard work of connecting, dealing, deciding, trying and telling suffices. Investments in developing leadership and networks among people with developmental disabilities and the families and their allies build the numbers of agents and thus the variety of copy-able strategies.

People with developmental disabilities and their allies have already invented a wonderful variety of strategies as they exercise agency. Such inventions include:

- Several ways of convening support circles and making plans that vividly describe the future a person desires and the things that matter most about how a person wants to live.
- Methods for individual people with developmental disabilities or family members recruiting, hiring, training, supervising, and paying assistants as their own employees.

- Ways of supporting families to found and operate a provider agency to serve their own sons and daughters within the same rates and rules that govern other service providers.
- Creating a co-operatively owned personal assistance agencies.
- Assisting small groups of people well known to and trusted by a person to form a micro-board, whose charter is to receive and spend available funds to assure that the person has necessary support to live a good life.
- Generating a growing array of dedicated services to assist individuals and families or small organizations with tasks like person-centered planning, negotiating individual budgets, locating and paying for housing, developing jobs, recruiting and training assistants, employing or co-employing assistants, or proving billing and payroll services.

When people with developmental disabilities and their families can form effective alliances with service providers, additional possibilities emerge. When understood as a complex adaptive system, the service world does not have to divide into controlling service users and controlled service providers any more than it has to divide into controlling service providers and controlled service users. Agency belongs to any combination of people and providers willing to jointly invent strategies for getting more of what they each value.

Engaging sophisticated customers

Service providers who want to invent the strategies necessary to offer customized assistance invest in identifying and engaging sophisticated customers (Rameriz and Wallin, 2000; Rockart, 2000). Sophisticated customers are more than paying customers. They know about what they want because they have carefully considered their own ideas about the kind of assistance they require through person-centered planning, they have used their connections to explore other's strategies, and they have taken steps for themselves. Sophisticated customers willingly negotiate the way a provider understands and responds to what matters in their lives. Sophisticated consumers expect conflicts and problems and look for creative resolutions. Sophisticated consumers expect to mobilize their own and other's resources to develop and maintain a great system of assistance.

Being a sophisticated customer demands a lot. It takes time and energy to learn about alternatives, plan, and negotiate for support arrangements that make sense. It takes even more time and energy, and often money, to maintain and continually improve the fit between evolving individual interests and assistance. Service brokers can make it easier to be a sophisticated customer

if they have the time, skills, and connections to do the job well. But unless service providers engage in a creative way, brokers independence from service provision limits broker's contributions to the everyday assistance people need. If they can't find providers willing to deal, brokers find themselves helping people either make the most of second-best or gather the will to create and manage their own assistance.

Some potential sophisticated customers have become their own service providers because they cannot find suitable collaborators. Others have been discouraged by intransigent providers and decided to settle for what is available. Still others lack opportunities to become sophisticated consumers because the weight of circumstances keeps them from the connections to other creative agents who could inform and encourage them.

Sophisticated customers embody many service providers' nightmares. They expect to set the agenda, they have their own ideas, they are quick to identify problems and insistent on problem resolution. They are often dissatisfied and vocal about it. Those service providers with the confidence and creativity to stretch themselves to collaborate with sophisticated customers will add to the stock of copy-able strategies for assisting people with developmental disabilities to lead satisfying lives as contributors to their communities.

Re-shaping the world

Paying customers are not enough. In order to create new possibilities for people with developmental disabilities and their allies to enjoy and contribute to community life, a growing number of people with disabilities and their families must make connections that will give them the knowledge and the courage to negotiate for the personally customized assistance they require. Customized assistance for growing numbers of different people in different circumstances will multiply the strategies available if the people involved take the time to reflect on and share what they are learning.

As more and more people with disabilities and their families make the transition from consumer to agent, life in neighborhoods, schools, workplaces, and civic spaces will –slowly at first– adapt in response to their varied contributions. In this way, people with disabilities and their allies will use individualized funding as one means to re-shape our world.

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